

A Qualitative Examination of Secondary Prophylaxis in Rheumatic Heart Disease

Factors Influencing Adherence to Secondary Prophylaxis in Uganda

Daniel M. Huck*, Haddy Nalubwama[†], Chris T. Longenecker[‡], Scott H. Frank[§], Emmy Okello^{||}, Allison R. Webel[¶]

Cleveland, OH, USA; and Kampala, Uganda

ABSTRACT

Background: Rheumatic heart disease (RHD) is the most common cause of heart disease among Ugandans age 15 to 49 years. Secondary prophylaxis with monthly injection of benzathine penicillin is effective in preventing recurrence of acute rheumatic fever and worsening of RHD, but adherence rates are poor in Uganda.

Objectives: This study sought to identify health behaviors, attitudes, and health care system factors that influence adherence to RHD secondary prophylaxis.

Methods: We conducted 5 structured focus groups with 36 participants on monthly penicillin injections for RHD in Kampala, Uganda. Transcripts were analyzed using qualitative description analysis and health behavior models.

Results: Most participants were female (64%), from an urban area (81%), and had family income less than US\$1 daily (69%). Ages ranged from 14 to 58 years. Median prophylaxis duration was 1.42 years and 58% were adherent ($\geq 80\%$ of injections). Key facilitators include perceived worsening of disease with missing injections, personal motivation, a reminder system for injections, supportive family and friends, and a positive relationship with health care providers. Barriers to adherence include lack of resources for transportation and medications, fear of injection pain, poor patient-provider communication, and poor availability of clinics and providers able to give injections.

Conclusions: We identified key facilitators and barriers to secondary prophylaxis for RHD from the patient perspective framed within the socioecological model. Our findings provide direction for intervention development to improve national RHD secondary prophylaxis.

Rheumatic heart disease (RHD) is among the most preventable cardiovascular diseases, yet 15 million people live with RHD worldwide. An estimated 1.4 million deaths worldwide per year are attributed to RHD, mostly in the developing world [1,2]. It is the most common cause of heart disease among the 15 to 49 years age group in Uganda [3]. Early detection and antibiotic treatment of group A streptococcal pharyngitis, primary prophylaxis, prevents the development of acute rheumatic fever and RHD. For those who develop RHD, secondary prophylaxis with monthly benzathine penicillin G intramuscular injections are the standard of care to prevent the recurrence of acute rheumatic fever and worsening of RHD [4–6]. However, a recent study in Uganda found that only 54% of patients received the recommended 80% of their monthly shots [7].

Several previous quantitative studies have explored determinants of adherence to secondary prophylaxis (benzathine penicillin G intramuscular injections). Investigators in New Caledonia identified a household of >5 people, medical history of symptomatic acute rheumatic fever, and adequate health coverage as facilitators for treatment adherence [8].

Another study in the Northern Territory of Australia found improved adherence among children, those with less severe disease, and more frequent attendees of clinic [9]. Also in Australia, a qualitative study of seven Aboriginal patients found that close long-term contact with health professionals aided adherence but remoteness from health care facilities, poor perception of medical staff's attitudes, and lack of a reminder system were detrimental [10]. Finally, a recent small quantitative study ($n = 95$) in Uganda found residence in an urban setting and having a secondary level of education facilitated adherence to secondary prophylaxis, whereas pain associated with injections and lack of transport money were barriers [7].

Our study sought to build on the existing body of evidence by qualitatively exploring how health behaviors and attitudes, as well as the health care system and its management, affect adherence to monthly prophylaxis. Given the limited evidence describing current barriers and facilitators to RHD secondary prophylaxis globally, it would have been difficult to use quantitative methodology instead of rigorous qualitative methodology, which allows for an in-depth investigation of these phenomena [11]. Our study also qualitatively explored

This study was funded by a grant from the Arnold P. Gold Foundation. Dr. Longenecker is supported by grants from the National Institutes of Health (#K23 HL123341), the Wolf Family Foundation Scholars Grant program, Medtronic Philanthropy, and Bristol-Myers Squibb. All other authors have reported no relationships that could be construed as a conflict of interest.

The study sponsor was not involved in the study design; the collection, analysis, or interpretation of the data; writing the manuscript; or the decision to submit it for publication.

Supplementary data associated with this article can be found, in the online version, at <http://dx.doi.org/10.1016/j.jgheart.2014.10.001>.

From the *School of Medicine, Case Western Reserve University, Cleveland, OH, USA; †School of Public Health, Makerere University, Kampala, Uganda; ‡Division of Cardiovascular Medicine, University Hospitals, Cleveland, OH, USA; §Department of Epidemiology and Biostatistics, Case Western Reserve University, Cleveland, OH, USA; ||Uganda Heart Institute, Mulago Hospital, Kampala, Uganda; and the ¶Frances Payne Bolton School of Nursing, Case Western Reserve University, Cleveland, OH, USA. Correspondence: A. R. Webel (Allison.webel@case.edu).

GLOBAL HEART
© 2015 World Heart Federation (Geneva).
Published by Elsevier Ltd.
All rights reserved.
VOL. 10, NO. 1, 2015
ISSN 2211-8160/\$36.00.
<http://dx.doi.org/10.1016/j.jgheart.2014.10.001>

how concurrent human immunodeficiency virus (HIV) infection and requirement for adherence to HIV antiretroviral therapy affects adherence to RHD monthly prophylaxis, given the high prevalence of HIV (5% to 10%) in Uganda [12].

METHODS

Participant recruitment

A total of 38 adults (>26 years) and adolescents/young adults (14 to 26 years) who receive monthly benzathine penicillin G intramuscular injections and are part of the RHD registry at the Uganda Heart Institute (UHI) formed the planned study population. Participants were consented and enrolled using quota sampling methodology. Participants at all levels of adherence were purposively enrolled in 5 groups and 3 categories: 2 groups of adults (>26 years); 2 groups of adolescents/young adults (14 to 26 years); and 1 group of HIV-positive participants. Approval was obtained from institutional review boards in Cleveland (University Hospitals) and Uganda (Makerere University).

Study design

This qualitative study consisted of semistructured focus groups of 6 to 8 participants. To facilitate discussion the interviewer (H.N., a Ugandan social worker who is an experienced interviewer and qualitative researcher) used a semistructured guide that employs key concepts from the literature on medication adherence in Africa. Focus group structure and content was grounded in the socioecological model of health. The socioecological model of health is grounded in work by Bronfenbrenner on ecological systems theory [13] and explores the intersection between individual, interpersonal and systemic factors and their impact on health. Sessions were led in the local language (Luganda) and digitally recorded. Standardized individual interviews to obtain background demographic and clinical information were conducted. Recordings were translated by H.N. and transcribed verbatim in English.

Setting

Focus groups were performed at the UHI, part of the national referral hospital in Kampala, Uganda. Participants were drawn from the RHD registry at the UHI.

Data analysis

Qualitative data was collected and transcribed and was associated with quantitative data such as demographics, treatment adherence, and HIV status. Using qualitative description analysis, two researchers (D.H. and A.W.) evaluated responses independently to identify patterns, themes, and important features, identify commonalities and differences, and develop codes for the data relevant to study variables, such as known facilitators and barriers to adherence, as well as codes describing new facilitators and barriers. ATLAS.ti software was used to manage data and assist in code development [14]. The investigators

discussed and resolved coding discrepancies. Quantitative data were described by frequencies, proportions, means or medians, and focus group themes were compared using Pearson chi-squared test or Fisher exact test.

RESULTS

Thirty-eight participants were recruited, constituting 5 focus groups of 6 to 8 participants. Two participants did not attend their assigned focus group, reducing the study sample to 36 participants. Participants were assigned to a focus group based on age (14 to 26 or >26 years). Once assigned to a group, 1 participant reported a different age than indicated in the medical chart; we kept that participant (a 25-year-old) in the assigned group (>26 years). Purposive recruitment of participants into different groups separated by adherence level was designed but did not occur because of limited information in medical charts about adherence. Most participants were female ($n = 23$, 64%), from an urban area ($n = 29$, 81%), and had family income less than US\$1 daily ($n = 25$, 69%). Ages ranged from 14 to 58 years. Median prophylaxis duration was 1.42 years and 58% were adherent ($\geq 80\%$ of injections). Additional demographic characteristics are in Table 1. Major facilitators and barriers are identified and summarized in Table 2 (see also Online Table 1) and described in the following sections.

Individual facilitators: worsening symptoms, personal motivation, reminder system

Participants frequently associated worsening of symptoms with missing injections, and improvement in how they felt with receiving the injection. Some said that they felt their “heart beating very fast,” “breathing [becoming] hard,” increased pain in the chest and joints, and fever after missing an injection. A 31-year-old man said, “But what I know is that these injections help a lot ... For my case, I tend to lose a lot of energy as the month is ending but after the injection, I regain it.” Others associated missing injections with more long term complications such as a 25-year-old woman: “[I come for injections] so as not to worsen the RHD disease or to control the disease from growing.”

Patients also expressed a personal motivation or responsibility to be healthy. A 56-year-old woman said, “you are fully responsible for your life and health” and a 26-year-old woman said, “When you follow the doctor’s recommendation, it helps you prolong your life as well as meet your future ambitions.”

Finally, participants used a variety of methods to remember their monthly appointments including a phone reminder, appointment receipts or medical documents, a card given by their health care provider to track injections, and reminders from family or friends.

Interpersonal facilitators: support from family, friends and health care providers

Participants frequently mentioned support from family and friends. A 21-year-old woman said, “my elder sister is also

TABLE 1. Sociodemographic characteristics of study participants (n = 36)

	n	Percentage
Age, yrs	31 ± 11	
Age, yrs	14–58	
Female	23	64
Unemployed	22	61
Urban	29	81
Household size	5 (3, 8)	
Rooms in house	3 (2, 4)*	
Distance from UHI, km	14 (8, 64)	
Within 10	16	44
>10–50	9	25
>50–100	3	8
>100	8	22
Education		
No education	2	6
Primary	13	36
Secondary	16	44
Vocational	1	3
University	4	11
Monthly income		
<50,000 (<US\$25)	25	69
50,000–99,000 (US\$25–US\$49)	1	3
100,000–199,000 (US\$50–US\$99)	3	8
200,000+ (US\$100)	7	19
Years on prophylaxis	1.42 (0.63, 2.5)	
Reported adherence in past 12 months, %	92 (50, 100)	
0–25	4	11
25–50	6	17
50–80	5	14
≥80	21	58
Mitral/aortic disease rate		
Mitral regurgitation	23	64
Mitral stenosis	16	44
Aortic regurgitation	11	31
Aortic stenosis	2	6
Heart medications used	3 (2, 4)	
Beta-blockers	21	58
Loop diuretics	27	75
Thiazides	2	6
ACEI	14	39
Spironolactone	5	14
Digoxin	10	28
Unspecified medication	9	25

Values are mean ± SD, range, n, or median (IQR).
ACEI, angiotensin-converting enzyme inhibitors; IQR, interquartile range; UHI, Uganda Heart Institute.
*Twenty-two participants had missing data for rooms in house.

always on my back!,” and a 43-year-old woman said, “one immediate friend ... normally reminds me of the injection.” A 30-year-old man said, “[Family members] tell me not to

worry myself. My parent spent a month when he was not eating during the time when I went for the heart operation.”

Family also frequently provided transportation and medication money and came with participants to their appointments.

Participants also valued the relationship with their health care providers. Participants cited their availability and compassion: a 21-year-old woman said, “I can even call [the doctor] at night and he attends me,” and a 33-year-old woman said, “these health workers do care about us.” A 31-year-old man expressed his opinion, “Despite us having different backgrounds (tribes), when he meets me in the corridors he puts on a smile for me and when I get to his desk, most of the pain I come with eases for a while.”

Systemic facilitators: close proximity to a clinic

Those participants who lived close to a clinic where they could receive penicillin injections cited this factor as a facilitator.

Individual barriers: lack of resources and injection pain/fear

Lack of resources for the medication and transportation was commonly mentioned. A 30-year-old male participant summarized, “The main issue is that the medicine is so expensive and the patients are poor people.” A 58-year-old female participant said, “One day I started feeling heart pain and the pain was too much. I went to a male doctor who told me that I should go to [the Uganda Heart Institute] and I told him that I didn’t have money so I stayed [away] for two years.” And a 34-year-old female participant from a rural area said, “I had three chickens that I sold and added on the little money I had to get the transport fare.”

Participants also described injections as “extremely painful” and expressed the desire for an anesthetic mixed with the injection, which was not always available. A 30-year-old man said, “In fact I feel bad knowing that I have to get the injection in the near future because of the painful injection process.”

Interpersonal barriers: relationships with family, friends, and health care providers

Participants mentioned that family and friends were “tired of treating us,” or thought that those with RHD are “lazy,” or that “heart disease was a death sentence.” Some participants lacked material support from family and friends such as transportation or money for appointments and injections. A 20-year-old woman said, “They, at times, reach a moment and they are tired of you. They don’t say it [to] my face but I can read their expression. They can be like, ‘why is it always this one giving us [a] hard time?’” A 19-year-old woman said, “[Family members] thought that I was going to die ... They also said that they didn’t have more money to waste on me.”

Bad rapport or misunderstandings with health care providers were also mentioned as barriers. For instance,

TABLE 2. Facilitators and barriers by focus group (n = 36)

Focus Group	Adult	Adult	Young Adult	Young Adult	HIV	
Participants, n	8	7	8	7	6	
Age, yrs, range	30–56	25–58	16–26	14–24	33–43	
Female	5 (63)	4 (57)	6 (75)	2 (29)	6 (100)	
Categories and Themes	Participant Frequency					Total (N = 36)
Individual facilitators						
Perceived increase in symptoms related to missing injection	6 (75)	7 (100)	7 (88)	7 (100)	5 (83)	32 (89)
Reminder system*	3 (38)	4 (57)	3 (38)	6 (86)	4 (67)	20 (56)
Personal motivation	3 (38)	0 (0)	6 (75)	3 (43)	3 (50)	15 (42)
Experience with or information about adherence to other daily medications	0 (0)	0 (0)	0 (0)	1 (14)	3 (50)	4 (11)
Individual barriers						
Lack of resources: money*	7 (88)	4 (57)	3 (38)	5 (71)	5 (83)	24 (67)
Lack of resources: transportation*	3 (38)	7 (100)	2 (25)	4 (57)	5 (83)	21 (58)
Injection pain and fear	3 (38)	1 (14)	7 (88)	3 (43)	4 (67)	18 (50)
Lack of perceived consequences from missing an injection	1 (13)	2 (29)	4 (50)	5 (71)	1 (17)	13 (36)
Attitude: not interested	1 (13)	0 (0)	3 (38)	1 (14)	0 (0)	5 (14)
HIV: multiple appointments or medication regimens	0 (0)	0 (0)	0 (0)	0 (0)	3 (50)	3 (8)
Interpersonal facilitators						
Family/friends: encouragement or material support	7 (88)	5 (71)	7 (88)	7 (100)	6 (100)	32 (89)
HC provider: good rapport/relationship	6 (75)	3 (43)	5 (63)	5 (71)	5 (83)	24 (67)
Interpersonal barriers						
Family/friends: stigma, lack of support, feeling of being a burden	5 (63)	6 (86)	7 (88)	6 (86)	5 (83)	29 (81)
HC provider: poor communication, bad rapport, distrust	6 (75)	6 (86)	7 (88)	6 (86)	1 (17)	26 (72)
Systemic facilitators						
Close proximity to clinic	0 (0)	3 (43)	1 (13)	2 (29)	0 (0)	6 (17)
Systemic barriers						
HC providers: poor availability of HC providers in local community	6 (75)	6 (86)	4 (50)	4 (57)	4 (67)	24 (67)
HC providers: not knowledgeable or unskilled	5 (63)	4 (57)	4 (50)	4 (57)	2 (33)	19 (53)
Penicillin shortage	1 (13)	3 (43)	2 (25)	4 (57)	3 (50)	13 (36)
HC providers: long wait for appointment	2 (25)	2 (29)	3 (38)	5 (71)	0 (0)	12 (33)

Values are number (%) of participants that mentioned each facilitator or barrier, unless otherwise indicated.
 HC, health care; HIV, human immunodeficiency virus.
 *These facilitators and/or barriers are also systemic.

lack of health care provider continuity impaired the patient-provider relationship. A 40-year-old male participant expressed his feelings, “[You could not] be open to this new doctor as you would be with your usual doctor.”

Patients expressed that health care providers did not always communicate the reason why they needed to take the injections. A 43-year-old woman said, “[other hospitals] ... just inject me without telling me anything.” Many participants did not know when they should stop taking injections. Language barriers between the patients and providers were also mentioned as barriers.

Systemic barriers: “there are no facilities and besides, they don’t have the medicine”

Participants frequently identified poor availability in their local community of skilled health care providers and/or

health clinics stocked with injectable penicillin. A 26-year-old woman said that “there are no facilities and besides, they don’t have the medicine” and a 56-year-old woman said, “one is always required to come to the city (Kampala) to get the drugs.” Participants also commented that providers were not knowledgeable or skilled. For instance, the “doctor/nurse feared to administer [the injection],” assumed they had another disease such as syphilis, “did not mix the drugs with lidocaine,” or told the patient to go to the capital hospital for their injection. A 30-year-old male commented, “They only tell you that they cannot manage [RHD] and they cannot treat it unless if [they look] at the cards where the injections instructions are and how it should be administered and the dose that they should give you.”

Participants were also dissuaded by long wait times for appointments. Participants said, “[you] sit for very long hours” and “you spend a day without seeing the doctor.”

A 33-year-old female participant mentioned that “The problem is that [patients] are very many and by the time you come, there may be other patients she has to work on who may even be worse off than you.”

Finally, shortages of penicillin were mentioned. A 45-year-old female said, “I had gotten expired drugs” and a 19-year-old female participant said, “There are times when they get out of stock in all of the clinics and the nearby hospital.”

Barrier or facilitator: lack of knowledge about RHD and injections

Inaccurate knowledge was common among participants. Some participants expressed lack of knowledge about the purpose of the penicillin injections or the need for monthly treatment. Many causes for RHD were cited including “fatty and oily things,” “smoke in kitchens,” “stress,” “family spirits,” “diet,” AIDS,” and “tuberculosis.” A frequently mentioned concept of causation was “over thinking,” “worrying so much,” and “a lot of thinking.” A 30-year-old male said, “I was born with [RHD]. When I asked my mother, she said that maybe it was due to the bomb blasts and tear gas during the war times that caused it since by that time I was still in her womb.”

Although there were many misconceptions about RHD among participants, a linkage between lack of knowledge and failure to get penicillin injections was not clearly evident. Many participants continued to get penicillin injections despite their limited understanding of the disease process.

Differences between younger and older RHD registry participants

Among the adolescent/young adult focus groups, when compared with older adults, injection pain and fear of pain (67% vs. 27%, $p = 0.028$) and lack of perceived consequences from missing an injection (60% vs. 20%, $p = 0.025$) were mentioned by a higher proportion of participants as barriers. Personal motivation or responsibility (60% vs. 20%, $p = 0.025$) was mentioned by a higher proportion of younger participants as a facilitator. More participants in the older adult group mentioned lack of money and transportation as barriers (70% vs. 47%), but the difference was not statistically significant.

Unique issues among the HIV community

Participants also living with HIV mentioned an additional barrier, having to be adherent to multiple medication regimens and attending multiple appointments, and an additional facilitator, experience with adherence to other medications. Overall, barriers and facilitators were similar to those of the other 4 focus groups.

DISCUSSION

This study among Ugandan adolescents and adults with RHD revealed a variety of facilitators and barriers to

adherence to secondary prophylaxis at the individual, interpersonal, and systemic levels. Figure 1 presents these findings within the socioecological model [13]. The findings suggest potential interventions at the various ecological levels in Uganda, and can be applied to other RHD-endemic resource-constrained countries. The current study is among the few qualitative studies studying RHD in this setting.

The current study has several strengths. Participants were drawn from the heart institute at the public national referral hospital of Uganda and came from places throughout the country. A range of sexes, socioeconomic statuses, and levels of adherence to penicillin injections were selected. This study provides important foundational evidence for interventions to improve adherence at the individual, interpersonal, and systemic level from the patients’ point of view.

There are limitations in this study. Because the study took place in an urban hospital, a majority of participants (81%) came from an urban area. In the country as a whole, 85% reside in a rural area [15]. Resource barriers and systemic access barriers are likely to be important among the rural population. Focus groups also do not lend themselves to assessment of certain stigmatized individual factors that may influence adherence such as coping

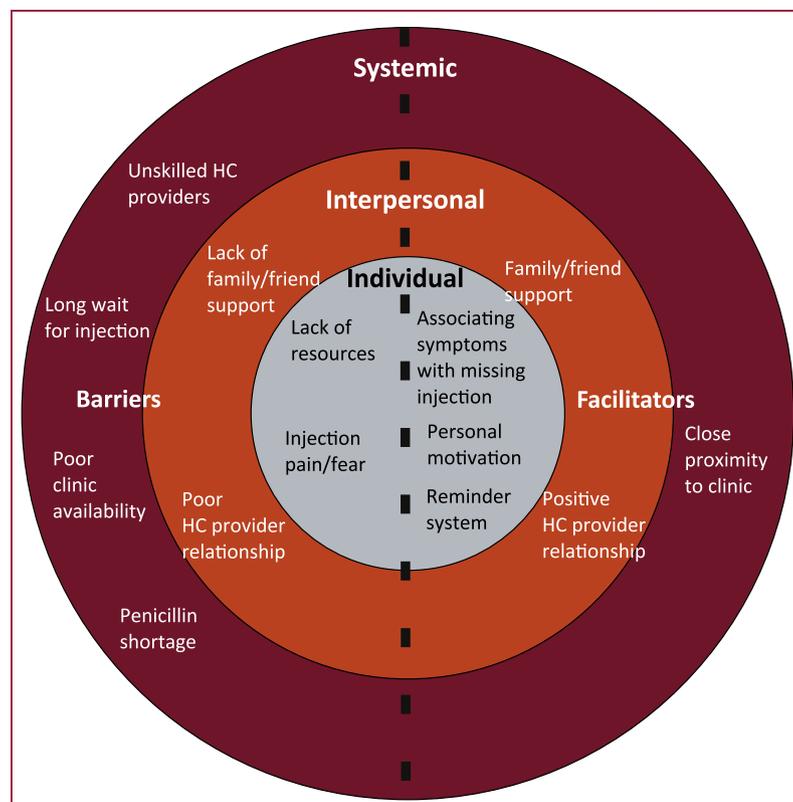


FIGURE 1. Facilitators and barriers in the socioecological model. HC, health care. Adapted, with permission, from Bronfenbrenner [13].

with stress, depression, and alcohol consumption. Many participants associated stress with causing or affecting their disease, and several participants mentioned abusive relationships with family affecting their adherence to injections. There is little reliable data about mental illness, stress, and substance abuse in Uganda. A 2012 World Health Organization report [16] and a study on consumption of alcoholic beverages among pregnant Ugandan women [17] suggest rates are high. A qualitative focus group study of mental health stakeholders in Uganda suggests stigma associated with mental illness can negatively affect health care utilization and increase risk of poverty [18]. Finally, language barriers and cultural differences between the Ugandan subjects and investigators may have affected conclusions. However, the use of an experienced Ugandan qualitative researcher as the focus group facilitator, and consultation with Ugandan experts during the analysis phase, helped limit this bias.

There are few qualitative studies of RHD secondary prophylaxis adherence in the literature, particularly in Africa. A study in Australia found similar factors to be important including the relationship with health professionals, distance from health care facilities, and monthly reminders [10]. However, resource constraints and pain with the injection were more prevalent factors in the Ugandan setting. In addition, the Ugandans in this study discussed the role of family and friends in their medical care. Much more qualitative research on adherence to HIV antiretroviral drugs has been performed. A recent literature review of HIV antiretroviral adherence in Africa highlighted transportation costs, distance, stigma, fear of drug toxicity, system factors such as waiting times and staff shortages, and demographic factors such as male sex and younger age [19]. Many of these factors were prominent in the current qualitative study, suggesting that many facilitators and barriers are common to both RHD and HIV. The responses of participants in the HIV-infected focus group of the current study were similar to the HIV-uninfected groups, reinforcing that these 2 diseases may overlap from a chronic disease management perspective. More work is needed to understand the context of chronic disease management, outside of HIV, in this setting.

Lack of resources including money and transportation and the pain of injections were frequently mentioned barriers and are similar to the findings from another study [7]. Almost one-quarter of participants in the current study travel >100 kilometers to receive injections, and a majority have family income less than US\$1 per day. These demographics reflect the key contribution of poverty on the ability to obtain RHD care. The long distances that participants traveled were often a result of another factor revealed in this study: limited availability of knowledgeable health care providers able to give penicillin injections in the local community. Participants expressed that they came to the national referral hospital in Kampala to get their injections because they could not access care in their local communities. They face long wait times on arrival, and

participants suggested that the system was overburdened by the number of patients needing care. Participants also frequently described injection pain, which may be related to poor injection technique. Based on the findings of this study, improving access to penicillin injections in the local community requires the following: 1) increasing supply of the injectable form of penicillin nationally; 2) training local health care providers on the best practices for giving penicillin injections; 3) increasing the capacity of regional and district hospitals and health centers to diagnose and treat RHD; and 4) easing the economic burden of health services and transportation for patients. These interventions would decrease the need for patients to travel long distances and lessen the overburdening of referral hospitals. In Uganda, existing national networks of treatment providers for HIV/acquired immunodeficiency syndrome already exist including the Joint Clinical Research Centre. Using existing models and infrastructure such as the Joint Clinical Research Centre could potentially reduce the time and resources necessary to provide penicillin injections in the local community of RHD patients in Uganda and in other resource-constrained settings. Relationships with family, friends, and health care providers were mentioned by participants as both barriers and facilitators. Educating family and friends about the disease and the need for injections may reduce stigma and improve the ability of these individuals to be supportive and help provide RHD care at home. Additional training of health workers about RHD can also improve rapport and trust of the medical community. Finally, widespread primary prevention campaigns similar to campaigns for prevention of HIV in Uganda are needed to target RHD patients, families, health care providers, and the society at large.

There are several unanswered questions that require further study. Misconceptions about RHD, its etiology and its treatment were common among participants, but the relationship with adherence was not always clear. Interestingly, participants associated worsening of RHD symptoms with missing a penicillin injection. It is unlikely that symptoms would acutely worsen after missing one injection. However, the perception of acute improvement of symptoms when getting an injection served as a facilitator to adherence in this study. Further exploration of the effect of knowledge on adherence to RHD secondary prophylaxis, including exploring the role of the KAP (Knowledge, Attitude, Practice) model and exploring differences between patient and health care provider explanatory models [20] can help frame health education efforts. Additional studies of the effect of the social environment and unaddressed psychological needs on RHD care are needed. Factors such as mental health, substance abuse, and physical and psychological abuse are likely important and certainly understudied in Uganda and throughout Africa. Study participants expressed overthinking as being causally related to RHD, similar to the cultural concept of distress described in Zimbabwe as “thinking too much” or “Kufungisisa.” “Kufungisisa” is linked with symptoms of

depression and anxiety in Zimbabwe and commonly co-occurs with somatic complaints such as pressure on the heart [21]. Finally, little is known about the cost effectiveness of different interventions to improve access to secondary prophylaxis. Additional economic feasibility studies are needed. The cost of improving the network of care should be weighed against the cost of worsening of RHD with missed injections and eventual treatment of heart failure, increased transportation costs, missed days of productive work, and strain on existing health care institutions.

CONCLUSIONS

This study identifies facilitators and barriers of adherence to secondary prophylaxis for RHD in Uganda framed within the socioecological model. It provides novel evidence from the patient perspective applicable to other RHD-endemic, resource-constrained countries.

Despite further study being needed, the current study already provides a strong base of qualitative evidence for interventions to improve adherence to secondary prophylaxis for RHD.

REFERENCES

1. Sliwa K, Zilla P. Rheumatic heart disease: the tip of the iceberg. *Circulation* 2012;125:3060–2.
2. Marijon E, Mirabel M, Celemajer DS, Jouven X. Rheumatic heart disease. *Lancet* 2012;379:953–64.
3. Okello E, Kakande B, Sebatta E, et al. Socioeconomic and environmental risk factors among rheumatic heart disease patients in Uganda. *PLoS One* 2012;7:e43917.
4. Manyemba J, Mayosi BM. Penicillin for secondary prevention of rheumatic fever. *Cochrane Database Syst Rev* 2002;(3):CD002227.
5. Gerber MA, Baltimore RS, Eaton CB, et al. Prevention of rheumatic fever and diagnosis and treatment of acute Streptococcal pharyngitis: a scientific statement from the American Heart Association Rheumatic Fever, Endocarditis, and Kawasaki Disease Committee of the Council on Cardiovascular Disease in the Young, the Interdisciplinary Council on Functional Genomics and Translational Biology, and the Interdisciplinary Council on Quality of Care and Outcomes Research. *Circulation* 2009;119:1541–51.
6. Pelajo CF, Lopez-Benitez JM, Torres JM, de Oliveira SKF. Adherence to secondary prophylaxis and disease recurrence in 536 Brazilian children with rheumatic fever. *Pediatr Rheumatol Online J* 2010;8:22.
7. Musoke C, Mondo CK, Okello E, et al. Benzathine penicillin adherence for secondary prophylaxis among patients affected with rheumatic heart disease attending Mulago Hospital. *Cardiovasc J Afr* 2013;24:124–9.
8. Gasse B, Baroux N, Rouchon B, Meunier JM, Frémicourt ID, D'Ortenzio E. Determinants of poor adherence to secondary antibiotic prophylaxis for rheumatic fever recurrence on Lifou, New Caledonia: a retrospective cohort study. *BMC Public Health* 2013;13:131.
9. Stewart T, McDonald R, Currie B. Acute rheumatic fever: adherence to secondary prophylaxis and follow up of Indigenous patients in the Katherine region of the Northern Territory. *Aust J Rural Health* 2007;15:234–40.
10. Mincham CB, Toussaint S, Mak DB, Plant AJ. Patient views on the management of rheumatic fever and rheumatic heart disease in the Kimberley: a qualitative study. *Aust J Rural Health* 2003;11:260–5.
11. Marshall C, Rossman BG. *Designing Qualitative Research*. 3rd edition. Thousand Oaks, CA: Sage Publications; 1999.
12. Kirby D. Changes in sexual behavior leading to the decline in the prevalence of HIV in Uganda: confirmation from multiple sources of evidence. *Sex Transm Infect* 2008;84(Suppl 2):ii35–41.
13. Bronfenbrenner U. Ecological models of human development. In: *International Encyclopedia of Education*. 2nd ed. Oxford, England: Elsevier Sciences, Ltd; 1994. p. 1643–7.
14. ATLAS.ti. Scientific Software Development GmbH. Version 7.1. Germany, Berlin. 2014.
15. Uganda Bureau of Statistics. Uganda National Household Survey 2009/2010. Available at: www.ubos.org/UNHS0910/unhs200910.pdf. Accessed March 24, 2014.
16. Ndyabangi S, Funk M, Ssebunnya J, et al. WHO proMIND: Profiles on Mental Health in Development. Republic of Uganda. Available at: www.who.int/mental_health/policy/country/uganda_country_summary_2012.pdf. Accessed March 24, 2014.
17. Namagembe I, Jackson LW, Zullo MD, Frank SH, Byamugisha JK, Sethi AK. Consumption of alcoholic beverages among pregnant urban Ugandan women. *Matern Child Health J* 2010;14:492–500.
18. Ssebunnya J, Kigozi F, Lund C, Kizza D, Okello E. Stakeholder perceptions of mental health stigma and poverty in Uganda. *BMC Int Health Hum Rights* 2009;9:5.
19. Govindasamy D, Ford N, Kranzer K. Risk factors, barriers and facilitators for linkage to antiretroviral therapy care: a systematic review. *AIDS* 2012;26:2059–67.
20. Kleinman A. Concepts and a model for the comparison of medical systems as cultural systems. *Soc Sci Med* 1978;12:85–95.
21. Patel V, Abas M, Broadhead J, Todd C, Reeler A. Depression in developing countries: lessons from Zimbabwe. *BMJ* 2001;322:482–4.

ONLINE TABLE 1. Facilitators and barriers by focus group (n = 36)

Focus Group	Adult	Adult	Young Adult	Young Adult	HIV			
Participants, n	8	7	8	7	6			
Age, yrs, range	30–56	25–58	16–26	14–24	33–43			
Female, n (%)	5 (63)	4 (57)	6 (75)	2 (29)	6 (100)			
Categories and Themes	Theme Frequency					Total (N = 36)		
Individual facilitators								
Perceived increase in symptoms related to missing injection			17	20	12	11	12	72
Reminder system*			4	5	3	7	4	23
Personal motivation			5	0	9	3	3	20
Experience with or information about adherence to other daily medications			0	0	0	1	4	5
Subtotal			26	25	24	22	23	120
Individual barriers								
Lack of resources: money*			18	5	7	10	8	48
Lack of resources: transportation*			4	7	2	12	7	32
Injection pain and fear			8	2	23	4	10	47
Lack of perceived consequences from missing an injection			1	3	6	6	1	17
Attitude: not interested			1	0	3	1	0	5
HIV: multiple appointments or medication regimens			0	0	0	0	6	6
Subtotal			32	17	41	33	32	155
Interpersonal facilitators								
Family/friends: encouragement or material support			15	10	30	20	13	88
HC provider: good rapport/relationship			10	5	5	8	5	33
Subtotal			25	15	35	28	18	121
Interpersonal barriers								
Family/friends: stigma, lack of support, feeling of being a burden			11	14	11	17	6	59
HC provider: poor communication, bad rapport, distrust			13	20	13	3	2	51
Subtotal			24	34	24	20	8	110
Systemic facilitators								
Close proximity to clinic			0	3	1	2	0	6
Systemic barriers								
HC providers: poor availability of HC providers in local community			9	13	10	17	14	64
HC providers: not knowledgeable or unskilled			6	4	8	4	5	27
Penicillin shortage			1	4	2	6	4	17
HC providers: long wait for appointment			4	2	5	13	0	24
Subtotal			20	23	25	40	23	132

Values are number of times each facilitator or barrier was mentioned, unless otherwise indicated.
 HC, health care; HIV, human immunodeficiency virus.
 *These facilitators and/or barriers are also systemic.